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Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?

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Title Page

Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?

A scoping literature review on the composition, collaboration, and ethical principles of multidisciplinary teams

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Conflict of interest

The authors declare no conflict of interest

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Key messages:

The consensus statement from 2006 introduced multidisciplinary teams in the care of people with variations of sex characteristics. The teams have been introduced in the care, but the composition and the collaboration of the teams remain unexplored. The present paper examined this gap. The results suggest that within the teams there is no real collaboration and that the teams are predominantly composed of medical professionals.

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Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?

A scoping literature review on the composition, collaboration, and ethical principles of multidisciplinary teams

Abstract

Background

In 2006 the Chicago consensus statement on the management of people with variations of sex characteristics (VSC) acknowledged the importance of a multidisciplinary team (MDT) approach. The consensus update from 2016 reinforced the call for multidisciplinary collaborations between medical professionals, parents and support groups, and proposed guidelines to improve shared decision making and patient centered care embedded in ethical principles of self-determination and child participation. But there is little evidence that successfully multidisciplinary teams have been implemented in clinical practice.

Methods and aims

A scoping review was conducted to identify studies that address the collaboration and decision making process of multidisciplinary teams providing care of people with VSC to identify ideal and actual (1) team composition (2) models of collaboration and (3) ethical principles that MDT teams follow. Six databases were systematically searched: CINAHL, Medline, Psychinfo, Scopus, Socindex and Web of Science. No restriction was placed on the type of methodology used in the studies. To frame the research, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses was used.

Results

The actual MDT teams include mainly medical professionals: endocrinologists, urologists and surgeons. The collaboration among medical professionals in multidisciplinary teams lacks cooperation as one team member – usually the endocrinologist – sets the tasks of the team while each professionals works separately. Despite the importance of psycho-social support the involvement of psychologists remains secondary. The implementation of ethical principles tends to exclude people with VSC.

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Conclusion

The care of people with VSC is medically oriented as the team members who are medical professionals who work separately. MDT tend to exclude people with VSC despite references to shared decision making processes and informed consent. There was no mention of adult care and lack of inclusion of patient's perspective in the care process. The future research should do more empirical research of MDTs.

Key words: multidisciplinary teams, shared decision making, people with variations of sex characteristics/differences of sex development (DSD), patient-centred care

Introduction

Variations of sex characteristics (VSC) demand a multidisciplinary care approach ¹, because human sex is determined by multiple factors ²: genetic, gonadal, hormonal, phenotypic, and psychological sex. The need to bring together a broad range of health care professionals to provide care for people with VSC has been recognized also by the Chicago consensus statement of 2006 ^{3,4}. The consensus statement has introduced new guidelines for the care of people with VSC and their families. These recommendations include: (1) the provision of long-term multidisciplinary care (including psycho-social support), open and on-going communication, the deferral of early cosmetic surgeries until the age of informed consent and the use of a new medical umbrella term DSD ^{3,5}. According to the consensus statement, multidisciplinary teams (MDT) are to include: (paediatric) endocrinologists, urologists, surgeons, psychiatrists/psychologists, gynaecologists, geneticists, neonatologists; and if available: social workers, nurses and medical ethicists ³. The MDT team should educate other health care professionals involved in the treatment of people with VSC, communicate with family members under supervision of a (health) care professional and develop a plan for clinical management ^{3,4,6}. Care should be patient-centered and focus on children's growing capabilities to participate in decisions regarding their health and thus pose a limit to parental authority ².

The updated consensus statement of 2016 seemed to recognize this important paradigm shift in children's rights by considering shared decision-making as "the crux of patient-centred care". Healthcare experts should share their knowledge but also their uncertainties in care and outcomes with patients and families and give them enough time and support to make fully informed decisions. A crucial aspect of this patient-centered, individualized care approach is the endorsement by the Chicago consensus of healthcare teams that are composed of different provider types. Such teams can be multidisciplinary, interdisciplinary and transdisciplinary depending on the degree of collaboration ⁴.

Although Lee and colleagues ⁴ explain the differences between these types of teams, they do not give any practical indications on how to set up such teams, nor do they explain which type of team is more suitable in which kind of context.

Studies suggest that regular MDT meetings may result in active deferral of early cosmetic surgeries⁷. On the one hand, data seems to suggest that the majority of teams in Europe accepts the MDT approach while other studies portray a less optimistic situation. Moreover, empirical data on the actual functioning of MDT, their collaboration with patients and families as well as their efficacy remain poorly documented ^{8,9}. It is often unclear, in fact, who is actually included in the team, what the role of each team member is, how various healthcare professionals collaborate, how people with VSC and their families are involved in the decision-making process regarding their health and what impact MDT have on care management and patient well-being.

The following paper aims to critically examine the existing scientific literature on the composition of MDT in the care of people with VSC, to describe the implementation of multidisciplinary teams in the care of people with VSC.

For this purpose, the manuscript aims to identify ideal and actual (1) MDT composition; (2) models of collaboration and (3) ethical principles that guide MDT teams. It further aims to identify possible barriers to the adequate implementation of MDT and examine any assessments of their impact on the care of persons with VSC. Finally, the review aims to identify possible gaps in the existing research on MDT.

Methods

Given the broad aim of the research question, a scoping review was conducted to provide an overview and critical analysis of the existing literature on MDT caring for people with VSC. We searched the following data bases: CINAHL, Medline, Psychinfo, Scopus, Socindex and Web of

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Science. The research terms were selected after discussions within the research team and extensive background reading on the topic (see Table 1). Inclusion criteria were: published in peer reviewed journals between 2006–2021, written in English, German or French. A 15-year publication window was chosen to capture all studies that were published after the publication of the Chicago consensus statement of 2006. In line with scoping reviews, no restriction was placed on they type of study (theoretical, intervention, quantitative, qualitative or mixed method) However, book chapters, literature reviews, expert reports, commentaries, conference abstracts and books were excluded. Given that in the medical community the acronym DSD is prevalent, we used it as a search term together with intersex. Terms such as “diverse sex development” and “variations of sex development” were not included in the search query because although these research terms are often relevant for affected persons and activists, they are not yet ingrained in the scientific literature and the preliminary searches gave no additional results when using these terms.

Table 1: Search query

Search terms	WoS	Scopus	Medline	CINAHL	Psychinfo	Socioindex
(intersex* OR "disorders of sex development" OR "differences of sex development" OR "genital ambiguity")	8,312	7,018	2,287	466	930	331
(child* OR minor* OR infant* OR newborn* OR baby OR babies OR paediatr* OR pediater* OR boy* OR girl* OR neonat* OR adolescent*)	4,111,869	2,875,699	1,258,637	523,079	541,804	132,823
(ethic* OR decision* OR issue* OR "decision making" OR "masculinizing surgery" OR "feminizing surgery" OR "genetic selection" OR "psychosocial support" OR "genital surgery" OR "surgical intervention" OR "hormone replacement therapy" OR standard* OR guidelines OR "best interest" OR harm* OR "human rights" OR autonom* OR assessment OR evaluation OR care OR medical management)	12,727,466	1,520,839	3,237,731	1,270,357	986,407	986,407
(multidisciplinary* OR interdisciplinary* OR interprofession* OR multilateral OR transdisciplinary* OR transprofession* OR holis*)	345,970	343,642	116,958	57,007	48,329	11,091
(intersex* OR "disorders of sex development" OR "differences of sex development" OR "genital ambiguity") AND (child* OR minor* OR infant* OR newborn* OR baby OR babies OR paediatr* OR pediater* OR boy* OR girl* OR neonat* OR adolescent*) AND (ethic* OR decision* OR issue* OR "decision making" OR "masculinizing surgery" OR "feminizing surgery" OR "genetic selection" OR "psychosocial support" OR "genital surgery" OR "surgical intervention" OR "hormone replacement therapy" OR standard* OR guidelines OR "best interest" OR harm* OR "human rights" OR autonom* OR assessment OR evaluation OR care OR medical management) AND (multidisciplinary* OR interdisciplinary* OR interprofession* OR multilateral OR transdisciplinary* OR transprofession* OR holis*)	189	102	82	26	14	2

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We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines ¹⁰ (see Figure 1). The combined research of 6 databases gave 415 results and 1 article was added through other sources. After deduplicating (using Zotero) 251 units remained and were further screened on the basis of title and abstract. The articles that referred to intersex or DSD, but did not refer to MDT were excluded. The screening process of the first author was checked and unified with the second author, who confirmed which articles were eligible based on the abstract. The first screening gave 35 results. After that the references of the already selected studies were checked to identify additional studies. This resulted in a final sample of 37 units. In the next step, the first and second author then read the full text versions of these articles. 25 records were excluded because they only loosely referred to MDT and either (1) failed to list which healthcare professionals are part of MDT; (2) made not reference to MDT collaboration models; (3) almost exclusively focused on the clinical management or psycho-social care of people with VSC; (4) or discussed the role of only one MDT member, without any description of their collaboration with other team members.

Figure 1: Search process using PRISMA Systematic Review of Literature

The data from the selected 12 articles was extracted by making a Microsoft Excel spreadsheet, secured and available to all team members. The spreadsheet included sections for authors name, year of publication, country of origin, name of the journal, study design, data analysis, key findings, patient age cohort, intersex variation, medical management, psychosocial care, composition of the team, approaches to collaboration, conceptual issues, ethical framework.

Results

1. General characteristics of included studies

Out of the final 12 articles 6 were theoretical ¹¹⁻¹⁶, 5 were empirical ¹⁷⁻²¹ and 1 was a mixed methods study ⁹. One third (4) of the articles was published in the UK ^{9,11,12,18}, the other third in the USA ^{13,15,17,20} and the remaining third came from Switzerland and Germany ²¹, Sweden and UK ¹⁹, Australia ¹⁶ and Germany ¹⁴ (see Table 2).

Table 2: Included Studies

Author	Year	Country	Study design	Patient cohort	Psychosocial care	Composition of team	Approaches to collaboration	Conceptual issues	Ethical framework
Ahmed et. al.	2016	UK	theoretical	adolescents	Clinical psychologist should examine early emotions of people with VSC, facilitate adjustment of parents to new-born, informed decision-making process.	endocrinologist, surgeon and/or urologist, clinical psychologist/psychiatrist, radiologist, nurse and neonatologist.	Paediatric endocrinologist should take the role of coordinator of sex assignment and decision-making process.	multidisciplinary	informed consent
Brain et. al.	2010	UK	theoretical	new-borns	Psychologist as mediator between physicians and patients	endocrinologist, (paediatric) urologist/surgeon, gynaecologist, psychologist, biochemist, clinical/molecular geneticist, ethicist	Psychologist has the crucial role, manages the process of communication between physicians and families	multidisciplinary	Informed consent and decision making
Chawla et. al.	2019	USA	empirical	an infant	Psychosocial support was provided: risk and benefits including the psychological consequences of having atypical genitalia were reviewed with the family.	endocrinologist, urologist, and paediatric, surgeon, clinical coordinator	clinical professional coordinates the team and shared decision-making process	multidisciplinary	Shared decision making
Gomez Lobo	2014	USA	theoretical	infants, children, adolescents	Psychosocial support should cover family support and facilitation of the decision-making process regarding medical treatment.	Physician, endocrinologist, nurse, counsellors, geneticist, paediatric urologist, surgeon, radiologist, bioethicist, gynaecologist - focus in this article.	A team coordinator is important in the creation of the service as well as ongoing functioning of the team and the team should educate other health care professionals	multidisciplinary	Shared decision making
Hiort et. al.	2014	D	theoretical	infants, children	/	endocrinologist, surgeon/urologist, psychologist, gynaecologist, geneticist, molecular biologist, radiologist, pathologist, biochemist.	Patient navigator coordinates communication between patients/families with the team.	multidisciplinary	informed consent
Kyriakou et. al.	2016	UK	empirical	children	/	paediatric endocrinologist, clinical geneticist, paediatrician, neonatologist, adult endocrinologist	Paediatric endocrinologist has the central role in the team.	multidisciplinary	Informed consent
Liao and Roen	2019	UK, SE	empirical	children	Psychologists' role is pushed aside in the begging of examination. The psychologist sometimes mediates the emotional mess to prevent patients from disengaging with the service.	gynaecologists, urologists, paediatric surgeons, endocrinologists, geneticists, psychologists and nurse specialists.	Team means a collection of specialists - there is no real collaboration, it is rather multi-professional.	multidisciplinary	/

Moran and Karkazis	2012	USA	theoretical	infants, children	psychiatrist, and/or social worker can provide early and ongoing psychosocial care and access to support resources for parents and patients.	paediatric endocrinologist, a paediatric urologist and/or surgeon, and a psychologist, psychiatrist, and/or social worker	The development of a team requires coordination in the planning, implementation, and functioning stages, and a team coordinator.	multidisciplinary	shared decision making.
Parisi et. al.	2007	USA	empirical	infants, children	Psychosocial support for families: parents are given pragmatic, age-appropriate recommendations for disclosure of a diagnosis of a DSD to a child in an honest, non-stigmatizing manner.	specialists in medical genetics, cytogenetics, gynaecology, and reproductive endocrinology and the paediatric specialties of urology, endocrinology, adolescent medicine, and psychiatry.	The role of geneticists is highlighted and in the initial stages coordinates the team.	multidisciplinary	shared decision making
Sanders et. al.	2017	UK	mixed method	children, adolescents	The nurse and psychologists are information exchange agents acting in an advocacy role.	Endocrinologist and geneticist were always present. In nine out of 10 clinics urologist and psychologist. Gynaecologists were present in seven clinics, while the nurse attended three clinics since only one site had a nurse as a consistent and integral member of the team.	Patients are also educators: general discussions about which topics or concerns were likely to be raised in clinic as issues based on connection to families helped professionals to “really think about what’s going to happen in a consultation.”	interprofessional	/
Streuli et. al	2012	CH, D	empirical	children	Psychosocial care is shared and provided or at least considered by all MDTs.	Paediatric endocrinologist, psychologist, specialist in sexual medicine, child and adolescent psychiatrist, paediatric surgeon, social worker, study nurse, gynaecologist, neonatologist, member of a support group	The team members collaborate with each other, family and the patient.	interprofessional (only pro forma), in reality it is multidisciplinary	shared and information based decision making process
Vora and Srinivasan	2010	AU	theoretical	neonates, children, adolescents	The (clinical) psychologist can aid in assessing the parents’ and young person’s understanding of information discussed and provide family support in a culturally sensitive manner.	endocrinologist, urologist, gynaecologist	The biomedical assessment is most often coordinated by the paediatric endocrinologist.	multidisciplinary	Informed consent?

Only two empirical studies^{17,18} addressed MDT in relation to a specific intersex variations: CAH and 46, XY DSD. Other studies either referred to a wide array of VSC:^{11–14,20} or provided no specification^{9,15,16,19,21} (see Table 2).

The majority of studies discussed MDTs in relation to infants and children^{12–15,17–21}. Two studies referred to children and adolescents^{9,16} and only one focused exclusively on adolescents¹¹. Overall the focus on adolescents was limited and none of the papers discussed MDT in relationship to adults (see Table 2).

Except for^{17,19} most studies referred to VSC in terms of disorders/differences of sex development and used the acronym without any critical reflection or explanation of it^{9,11–16,18,20,21}. Two papers explicitly referred to VSC as a pathology^{11,16}.

2. The ideal and actual composition of MDT.

According to most theoretical studies MDT ideally consist of an endocrinologist, an urologist, and a surgeon^{11–16}. Some papers also include geneticists^{11–14}, psychologists^{11–15}, gynaecologists^{12–14,16} and radiologists^{11,13,14}.

However in practice, the core team was composed of endocrinologists^{9,17–21}, accompanied almost always by urologists/surgeons^{9,17,19–21}, geneticists^{9,18–20}, gynaecologists^{9,19–21} and psychologist/psychiatrists^{9,19–21}.

The vast majority of articles considered multiple methods of medical management as being the task of MDTs: genetic testing (including karyotyping), biomedical assessment (such as hormone levels, blood and urine tests), genital surgery and ultrasounds^{11–14,16–21}. Less than half of the papers suggest that in the MDTs each specialist is singularly responsible for the medical management^{11–14,17}. Half of the papers did not specify the responsibility for medical management^{9,16,18–21}. Only one paper¹⁵ argued that specialists should talk to each other about their medical tasks and collaborate with coordinator.

Next to medical management, psychosocial care was considered by 6 articles to be a key task of MDT. This role was mostly ascribed to psychologists^{9,11–13,16,19}. In only one paper psychosocial care was said to be provided by all the members of the team²¹.

Most studies focused on the importance of psychosocial support for parents to help them cope with their child being intersex^{11,13,16}. Psychologists should provide them information, connect parents them to support groups^{13,16} and function as mediators between parents and health care

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professionals to facilitate the decision-making process ^{12,13}. Ahmed and colleagues ¹¹ argued that psychosocial support ought to be provided to people with variations of sex characteristics in general to help them cope with the whole process. Only one empirical study ¹⁹ focused on psychosocial support as part of MDT. The authors found out that in the initial phases of the multidisciplinary care psycho-social counselling is secondary to medical treatment. What is more psychologists rarely collaborate with medical professionals and the former take on reconciliatory role between medical professionals, patients and parents in the last stages of the care process.

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3. Models of collaboration & barriers

In most studies^{17–21 11–16} the model of collaboration – multidisciplinary, interdisciplinary or transdisciplinary - was not explicitly mentioned. Still most of the papers seemed to indicate a multidisciplinary approach in MDTs described as the simultaneous but independent contribution of two or more team members. Two empirical studies^{21 22} and the mixed methods study⁹ show that although participants referred to their team as a MDT or even interprofessional, their responses reflect a disintegrated approach.

In most studies, interaction among team members was mediated by a team coordinator who was responsible for delegating and reviewing tasks^{11–18,20}. The coordinator was usually one of the following specialists: endocrinologists^{11,16,18}, geneticists²⁰, a physician¹³, social worker¹⁵, or psychologist¹². Only in the study of Streuli and colleagues²¹ the MDT collaborated and cooperated with patients and parents without the mediation of a coordinator.

In most empirical^{17–21} and theoretical^{11–16} articles the model of collaboration was not explicitly mentioned but most of the papers seem to indicate that MDTS take a multidisciplinary approach insofar the teamwork was described as the simultaneous and independent contribution of two or more team members. Only the mixed methods study of Sanders and colleagues⁹ included an interprofessional team approach where patients, parents and members of the MDT actively cooperate in the treatment process in order to co-create knowledge and improve the care of people with VSC and help parents cope with their child's condition.

As Liao and Roen¹⁹ pointed out medical professionals have more important role than psychologists whose work is seen as non-intervention because it is not medical and it is as such often side-lined.

The most often mentioned barriers to multidisciplinary collaboration were lack of financial, organisational and financial resources at hospitals and care centres for MDTS to be implemented and registered^{11–14,18}. The key barrier to collaboration, e. g. formation of MDTS in these centres is the lack of specialists^{9,12,13,18}. One fourth of the papers^{9,12,21} stressed the absence of confidentiality between team members, patients and parents as a barrier to collaboration process. Two papers^{14,20} pointed out the difficulties of diagnosis. The lack of cooperation between medical professionals and psychologists and prevalence of medicalised approach was highlighted as a barrier in one case¹⁹. Only one study²¹ pointed out the emotional

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distancing and difficulties of medical professionals to distinguish facts from assumptions as obstacle to collaboration process. One fourth ¹⁵⁻¹⁷ of the papers did not specify any barriers to collaboration process.

4. Ethical principles of MDT teams

The most commonly cited ethical principles were informed consent ^{11,12,14,16}, and shared decision-making ^{13,15,17,18,20,21}. However, only a minority ^{9,11,12,17} of papers provided an account of implementation of these two ethical principles. The papers ^{9,11,12,17} stated that parents needed to be educated about the condition of their child and that parental fears need to be considered in the decision making process. Yet there was lack of mention of how patients themselves growing up should be educated about their condition and actively involved in the decision-making process. Only two papers mentioned the involvement of patients in the decision making process ^{11,15}. Two papers ^{13,20} emphasized that the communication between MDT and parents/patients in the process of making an ethical decision should be open and should include the concerns of parents, but not children.

Discussion

The scoping review identified 12 studies that either empirically or theoretically provided an account of multidisciplinary teams caring for patients with VSC. Almost all articles stressed the importance of MDT, but under closer examination the exact nature of collaboration remained unclear. The prevalent approach seemed to be multidisciplinary, that is, collaboration in which different care providers work simultaneously but separately. The papers rarely elaborated on implementation of multidisciplinary let alone critically examine it. Research on MDT in other healthcare contexts suggests that it is not enough to have a unit of different health care professionals working together ^{23,24}, but the responsibility, knowledge and authority should be flexibly shared and team members should believe in cooperation ^{23,25-27}. However, the studies in our scoping review failed to address these suggestions as there are no indicators to assess the impact of the MDT which could lead to improved care for people with VSC. The teamwork is usually coordinated by an endocrinologist, physician, and in a few instances by a psychologist, even though this was not always empirically assessed, because the exact nature of the relationships withing the teams and their working practices were not revealed. The papers

clearly demonstrate the dominance of medical professionals over other healthcare experts and psychosocial care in the core teams which necessarily include endocrinologists, urologists, and surgeon and to lesser extent psychologists, social worker, and ethicist.

Our scoping review confirmed the findings that tendency toward a more medical-oriented structure (predominance of doctors in the teams) of multidisciplinary teams leads to poor collaboration and efficacy^{27,28}.

This was also partly confirmed by data on psychological support which is thought of and provided in terms of alleviating emotional distress of parents facing the fact that they have a child with VSC. Psychological support is provided to mediate relations between families and medical professionals, but it seen as addition to the treatment provided by medical professionals.

The account of psychological support revealed absence of child-centred approach and a lack of combined child centred approach with family-oriented care as there was no mention of what kind psychological support is provided for people with VSC, but only for their families. This was reverberated in ethical principles as only two papers mentioned that the decision making process and informed consent should include people with VSC. This might be due to the fact that the majority of papers focused on infants. Even though the majority of papers focused on children and adolescents, these studies failed to address the role and implementation of shared decision making for them. There was no mention of transition of care from adolescence to adulthood. None of the studies focused on the care of adults.

The lack of inclusion of patients' perspective and preferences in the treatment of people with VSC and shared decision making process is consistent with previous findings. According to these findings health care professionals stated that patient's perspectives should be an important part of the meetings of the MDT, but do not consider it beneficial to the meetings of MDTs²⁸. It is seen to be at the odds with professionals standards, and what is more medical professionals conflate shared decision making process with informed consent or there is no awareness of the former term²⁹. Although some papers aimed to advocate for approach according to which teams educate their patients and even learn from them – the interprofessional approach which seems to de-hierarchize the knowledge relations between patients and medical professionals – they remain a minority within the current literature on medical collaboration in multidisciplinary teams working with people with VSC⁹.

Limitations

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Some relevant studies might have been overlooked due to exclusion/inclusion criteria and the fact that there are no validated or openly discussed indicators of their quality. Nevertheless, our review provides an overview of the existing literature on collaboration of MDT caring for people with VSC and provides important directions for further research that will hopefully lead to better care of people with VSC. Therefore, we propose the more empirical research on the role of health care professionals in MDTs and more research on MDTs and adult care.

Conclusion

Teams caring for people with VSC are multidisciplinary as they consist of many different medical professionals working side by side. The collaboration among them lacks cooperation and synthesized discipline approach as one team member – usually a medical professional (an endocrinologist, a geneticist or a physician), rarely a psychologist or a social worker, coordinates the management process while the rest of the team members seem to work separately. Only a minority of team members come from disciplines such as social work or psychology. The most frequently cited ethical principles are shared decision making and informed consent, but both tend to focus on parents rather than on patients. Future studies should pursue empirical research on MDT by examining in the detail the process of shared decision making between MDT, parents, adults and children.

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Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?

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Title Page

Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?

A scoping literature review on the composition, collaboration, and ethical principles of multidisciplinary teams

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Conflict of interest

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Key messages:

The consensus statement from 2006 introduced multidisciplinary teams in the care of people with variations of sex characteristics. The teams have been introduced in the care, but the composition and the collaboration of the teams remain unexplored. The present paper examined this gap. The results suggest that within the teams there is no real collaboration and that the teams are predominantly composed of medical professionals.

Confidential: For Review Only

Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?

A scoping literature review on the composition, collaboration, and ethical principles of multidisciplinary teams

Abstract

Background

In 2006 the Chicago consensus statement on the management of people with variations of sex characteristics (VSC) acknowledged the importance of a multidisciplinary team (MDT) approach. The consensus update from 2016 reinforced the call for multidisciplinary collaborations between medical professionals, parents and support groups, and proposed guidelines to improve shared decision making and patient centered care embedded in ethical principles of self-determination and child participation. But there is little evidence that successfully multidisciplinary teams have been implemented in clinical practice.

Methods and aims

A scoping review was conducted to identify studies that address the collaboration and decision making process of multidisciplinary teams providing care of people with VSC to identify ideal and actual (1) team composition (2) models of collaboration and (3) ethical principles that MDT teams follow. Six databases were systematically searched: CINAHL, Medline, Psychinfo, Scopus, Socindex and Web of Science. No restriction was placed on the type of methodology used in the studies. To frame the research, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses was used.

Results

The MDT teams in the literature include mainly medical professionals: endocrinologists, urologists and surgeons. The collaboration among medical professionals in multidisciplinary teams lacks cooperation as one team member sets the tasks of the team while each professional works separately. Despite the importance of psycho-social support the involvement of psychologists remains secondary. The implementation of ethical principles tends to exclude people with VSC.

Conclusion

The care of people with VSC described in the papers is medically oriented as the team members are mainly medical professionals working separately. MDT tend to exclude people with VSC despite references to shared decision making processes and informed consent. There was no mention of adult care and lack of inclusion of patient's perspective in the care process. The future research should do more empirical research of MDTs.

Key words: multidisciplinary teams, shared decision making, people with variations of sex characteristics/differences of sex development (DSD), patient-centred care

Introduction

Variations of sex characteristics (VSC) demand a multidisciplinary care approach ¹, because human sex is determined by multiple factors ²: genetic, gonadal, hormonal, phenotypic, and psychological sex. The need to bring together a broad range of health care professionals to provide care for people with VSC has been recognized also by the Chicago consensus statement of 2006 ^{3,4}. The consensus statement has introduced new guidelines for the care of people with VSC and their families. These recommendations include: (1) the provision of long-term multidisciplinary care (including psycho-social support), open and on-going communication, the deferral of early cosmetic surgeries until the age of informed consent and the use of a new medical umbrella term DSD ^{3,5}. According to the consensus statement, multidisciplinary teams (MDT) are to include: (paediatric) endocrinologists, urologists, surgeons, psychiatrists/psychologists, gynaecologists, geneticists, neonatologists; and if available: social workers, nurses and medical ethicists ³. The MDT team should educate other health care professionals involved in the treatment of people with VSC, communicate with family members under supervision of a (health) care professional and develop a plan for clinical management ^{3,4,6}. Care should be patient-centered and focus on children's growing capabilities to participate in decisions regarding their health and thus pose a limit to parental authority ².

The updated consensus statement of 2016 seemed to recognize this important paradigm shift in children's rights by considering shared decision-making as "the crux of patient-centred care". Healthcare experts should share their knowledge but also their uncertainties in care and outcomes with patients and families and give them enough time and support to make fully informed decisions.

A crucial aspect of this patient-centered, individualized care approach is the endorsement by the Chicago consensus of healthcare teams that are composed of different provider types. Such teams can be multidisciplinary, interdisciplinary and transdisciplinary depending on the degree of collaboration⁴. The Chicago consensus does not specify which MDT would be the most appropriate. However the 2016 update defines types of collaboration in detail. In multidisciplinary teams two or more team members work simultaneously but separately; interdisciplinary teams involve the joint work of professionals from different disciplines sharing knowledge and skills to address a common problem and in transdisciplinary teams various disciplines are brought together to create new ways of solving problems and share responsibility of care⁴. Although Lee and colleagues⁴ explain the differences between these types of teams, they do not give any practical indications on how to set up such teams, nor do they explain which type of team is more suitable in which kind of context.

Studies suggest that regular MDT meetings may result in active deferral of early cosmetic surgeries⁷. On the one hand, data seems to suggest that the majority of teams in Europe accepts the MDT approach while other studies portray a less optimistic situation. Moreover, empirical data on the actual functioning of MDT, their collaboration with patients and families as well as their efficacy remain poorly documented^{8,9}. It is often unclear, in fact, who is actually included in the team, what the role of each team member is, how various healthcare professionals collaborate, how people with VSC and their families are involved in the decision-making process regarding their health and what impact MDT have on care management and patient well-being.

The following paper aims to critically examine the existing scientific literature on the composition of MDT in the care of people with VSC, to describe the implementation of multidisciplinary teams in the care of people with VSC.

For this purpose, the manuscript aims to identify ideal and actual (1) MDT composition; (2) models of collaboration and (3) ethical principles that guide MDT teams. It further aims to identify possible barriers to the adequate implementation of MDT and examine any assessments of their impact on the care of persons with VSC. Finally, the review aims to identify possible gaps in the existing research on MDT.

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Methods

Given the broad aim of the research question, a scoping review was conducted to provide an overview and critical analysis of the existing literature on MDT caring for people with VSC. We searched the following data bases: CINAHL, Medline, Psychinfo, Scopus, Socindex and Web of Science. The research terms were selected after discussions within the research team and extensive background reading on the topic (see Table 1). Inclusion criteria were: published in peer reviewed journals between 2006–2021, written in English, German or French. A 15-year publication window was chosen to capture all studies that were published after the publication of the Chicago consensus statement of 2006. In line with scoping reviews, no restriction was placed on they type of study (theoretical, intervention, quantitative, qualitative or mixed method) However, book chapters, literature reviews, expert reports, commentaries, conference abstracts and books were excluded. Given that in the medical community the acronym DSD is prevalent, we used it as a search term together with intersex. Terms such as “diverse sex development” and “variations of sex development” were not included in the search query because although these research terms are often relevant for affected persons and activists, they are not yet ingrained in the scientific literature and the preliminary searches gave no additional results when using these terms.

Table 1: Search query

Search terms	WoS	Scopus	Medline	CINAHL	Psychinfo	Socioindex
(intersex* OR "disorders of sex development" OR "differences of sex development" OR "genital ambiguity")	8,312	7,018	2,287	466	930	331
(child* OR minor* OR infant* OR newborn* OR baby OR babies OR paediatr* OR pediater* OR boy* OR girl* OR neonat* OR adolescent*)	4,111,869	2,875,699	1,258,637	523,079	541,804	132,823
(ethic* OR decision* OR issue* OR "decision making" OR "masculinizing surgery" OR "feminizing surgery" OR "genetic selection" OR "psychosocial support" OR "genital surgery" OR "surgical intervention" OR "hormone replacement therapy" OR standard* OR guidelines OR "best interest" OR harm* OR "human rights" OR autonom* OR assessment OR evaluation OR care OR medical management)	12,727,466	1,520,839	3,237,731	1,270,357	986,407	986,407
(multidisciplinary* OR interdisciplinary* OR interprofession* OR multilateral OR transdisciplinary* OR transprofession* OR holis*)	345,970	343,642	116,958	57,007	48,329	11,091
(intersex* OR "disorders of sex development" OR "differences of sex development" OR "genital ambiguity") AND (child* OR minor* OR infant* OR newborn* OR baby OR babies OR paediatr* OR pediater* OR boy* OR girl* OR neonat* OR adolescent*) AND (ethic* OR decision* OR issue* OR "decision making" OR "masculinizing surgery" OR "feminizing surgery" OR "genetic selection" OR "psychosocial support" OR "genital surgery" OR "surgical intervention" OR "hormone replacement therapy" OR standard* OR guidelines OR "best interest" OR harm* OR "human rights" OR autonom* OR assessment OR evaluation OR care OR medical management) AND (multidisciplinary* OR interdisciplinary* OR interprofession* OR multilateral OR transdisciplinary* OR transprofession* OR holis*)	189	102	82	26	14	2

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We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines ¹⁰ (see Figure 1). The combined research of 6 databases gave 415 results and 1 article was added through other sources. After deduplicating (using Zotero) 251 units remained and were further screened on the basis of title and abstract. The articles that referred to intersex or DSD, but did not refer to MDT were excluded. The screening process of the first author was checked and unified with the second author, who confirmed which articles were eligible based on the abstract. The first screening gave 35 results. After that the references of the already selected studies were checked to identify additional studies. This resulted in a final sample of 37 units. In the next step, the first and second author then read the full text versions of these articles. 25 records were excluded because they only loosely referred to MDT and either (1) failed to list which healthcare professionals are part of MDT; (2) made not reference to MDT collaboration models; (3) almost exclusively focused on the clinical management or psycho-social care of people with VSC; (4) or discussed the role of only one MDT member, without any description of their collaboration with other team members.

Figure 1: Search process using PRISMA Systematic Review of Literature

The data from the selected 12 articles was extracted by making a Microsoft Excel spreadsheet, secured and available to all team members. The spreadsheet included sections for authors name, year of publication, country of origin, name of the journal, study design, data analysis, key findings, patient age cohort, intersex variation, medical management, psychosocial care, composition of the team, approaches to collaboration, conceptual issues, ethical framework.

Results

1. General characteristics of included studies

Out of the final 12 articles 6 were theoretical ¹¹⁻¹⁶, 5 were empirical ¹⁷⁻²¹ and 1 was a mixed methods study ⁹. One third (4) of the articles were published in the UK ^{9,11,12,18}, the other third in the USA ^{13,15,17,20} and the remaining third came from Switzerland and Germany ²¹, Sweden and UK ¹⁹, Australia ¹⁶ and Germany ¹⁴ (see Table 2).

Table 2: Included Studies

Author	Year	Country	Study design	Patient cohort	Psychosocial care	Composition of team	Approaches to collaboration	Conceptual issues	Ethical framework
Ahmed et. al.	2016	UK	theoretical	adolescents	Clinical psychologist should examine early emotions of people with VSC, facilitate adjustment of parents to new-born, informed decision-making process.	endocrinologist, surgeon and/or urologist, clinical psychologist/psychiatrist, radiologist, nurse and neonatologist.	Paediatric endocrinologist should take the role of coordinator of sex assignment and decision-making process.	multidisciplinary	informed consent
Brain et. al.	2010	UK	theoretical	new-borns	Psychologist as mediator between physicians and patients	endocrinologist, (paediatric) urologist/surgeon, gynaecologist, psychologist, biochemist, clinical/molecular geneticist, ethicist	Psychologist has the crucial role, manages the process of communication between physicians and families	multidisciplinary	Informed consent and decision making
Chawla et. al.	2019	USA	empirical	an infant	Psychosocial support was provided: risk and benefits including the psychological consequences of having atypical genitalia were reviewed with the family.	endocrinologist, urologist, and paediatric, surgeon, clinical coordinator	clinical professional coordinates the team and shared decision-making process	multidisciplinary	Shared decision making
Gomez Lobo	2014	USA	theoretical	infants, children, adolescents	Psychosocial support should cover family support and facilitation of the decision-making process regarding medical treatment.	Physician, endocrinologist, nurse, counsellors, geneticist, paediatric urologist, surgeon, radiologist, bioethicist, gynaecologist - focus in this article.	A team coordinator is important in the creation of the service as well as ongoing functioning of the team and the team should educate other health care professionals	multidisciplinary	Shared decision making
Hiort et. al.	2014	D	theoretical	infants, children	/	endocrinologist, surgeon/urologist, psychologist, gynaecologist, geneticist, molecular biologist, radiologist, pathologist, biochemist.	Patient navigator coordinates communication between patients/families with the team.	multidisciplinary	informed consent
Kyriakou et. al.	2016	UK	empirical	children	/	paediatric endocrinologist, clinical geneticist, paediatrician, neonatologist, adult endocrinologist	Paediatric endocrinologist has the central role in the team.	multidisciplinary	Informed consent
Liao and Roen	2019	UK, SE	empirical	children	Psychologists' role is pushed aside in the begging of examination. The psychologist sometimes mediates the emotional mess to prevent patients from disengaging with the service.	gynaecologists, urologists, paediatric surgeons, endocrinologists, geneticists, psychologists and nurse specialists.	Team means a collection of specialists - there is no real collaboration, it is rather multi-professional.	multidisciplinary	/

Moran and Karkazis	2012	USA	theoretical	infants, children	psychiatrist, and/or social worker can provide early and ongoing psychosocial care and access to support resources for parents and patients.	paediatric endocrinologist, a paediatric urologist and/or surgeon, and a psychologist, psychiatrist, and/or social worker	The development of a team requires coordination in the planning, implementation, and functioning stages, and a team coordinator.	multidisciplinary	shared decision making.
Parisi et. al.	2007	USA	empirical	infants, children	Psychosocial support for families: parents are given pragmatic, age-appropriate recommendations for disclosure of a diagnosis of a DSD to a child in an honest, non-stigmatizing manner.	specialists in medical genetics, cytogenetics, gynaecology, and reproductive endocrinology and the paediatric specialties of urology, endocrinology, adolescent medicine, and psychiatry.	The role of geneticists is highlighted and in the initial stages coordinates the team.	multidisciplinary	shared decision making
Sanders et. al.	2017	UK	mixed method	children, adolescents	The nurse and psychologists are information exchange agents acting in an advocacy role.	Endocrinologist and geneticist were always present. In nine out of 10 clinics urologist and psychologist. Gynaecologists were present in seven clinics, while the nurse attended three clinics since only one site had a nurse as a consistent and integral member of the team.	Patients are also educators: general discussions about which topics or concerns were likely to be raised in clinic as issues based on connection to families helped professionals to “really think about what’s going to happen in a consultation.”	interprofessional	/
Streuli et. al	2012	CH, D	empirical	children	Psychosocial care is shared and provided or at least considered by all MDTs.	Paediatric endocrinologist, psychologist, specialist in sexual medicine, child and adolescent psychiatrist, paediatric surgeon, social worker, study nurse, gynaecologist, neonatologist, member of a support group	The team members collaborate with each other, family and the patient.	interprofessional (only pro forma), in reality it is multidisciplinary	shared and information based decision making process
Vora and Srinivasan	2010	AU	theoretical	neonates, children, adolescents	The (clinical) psychologist can aid in assessing the parents’ and young person’s understanding of information discussed and provide family support in a culturally sensitive manner.	endocrinologist, urologist, gynaecologist	The biomedical assessment is most often coordinated by the paediatric endocrinologist.	multidisciplinary	Informed consent?

Only two empirical studies^{17,18} addressed MDT in relation to a specific VSC: CAH and 46, XY DSD. Other studies either referred to a wide array of VSC: ^{11–14,20} or provided no specification ^{9,15,16,19,21} (see Table 2).

The majority of studies discussed MDTs in relation to infants and children ^{12–15,17–21}. Two studies referred to children and adolescents ^{9,16} and only one focused exclusively on adolescents ¹¹. Overall the focus on adolescents was limited and none of the papers discussed MDT in relationship to adults (see Table 2).

Except for ^{17,19} most studies referred to VSC in terms of disorders/differences of sex development and used the acronym without any critical reflection or explanation of it ^{9,11–16,18,20,21}. Two papers explicitly referred to VSC as a pathology ^{11,16}.

2. The ideal and actual composition of MDT.

According to most theoretical studies MDT ideally consist of an endocrinologist, an urologist, and a surgeon ^{11–16}. Some papers also include geneticists ^{11–14}, psychologists ^{11–15}, gynaecologists ^{12–14,16} and radiologists ^{11,13,14}.

However in practice, the core team was composed of endocrinologists ^{9,17–21}, accompanied almost always by urologists/surgeons ^{9,17,19–21}, geneticists ^{9,18–20}, gynaecologists ^{9,19–21} and psychologist/psychiatrists ^{9,19–21}.

The vast majority of articles considered multiple methods of medical management as being the task of MDTs: genetic testing (including karyotyping), biomedical assessment (such as hormone levels, blood and urine tests), genital surgery and ultrasounds ^{11–14,16–21}. Less than half of the papers suggest that in the MDTs each specialist is singularly responsible for the medical management ^{11–14,17}. Half of the papers did not specify the responsibility for medical management ^{9,16,18–21}. Only one paper ¹⁵ argued that specialists should talk to each other about their medical tasks and collaborate with coordinator.

Next to medical management, psychosocial care was considered by 6 articles to be a key task of MDT. This role was mostly ascribed to psychologists ^{9,11–13,16,19}. In only one paper psychosocial care was said to be provided by all the members of the team ²¹.

Most studies focused on the importance of psychosocial support for parents to help them cope with their child being intersex ^{11,13,16}. Psychologists should provide them information, connect parents them to support groups ^{13,16} and function as mediators between parents and health care

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professionals to facilitate the decision-making process ^{12,13}. Ahmed and colleagues ¹¹ argued that psychosocial support ought to be provided to people with VSC in general to help them cope with the whole process. Only one empirical study ¹⁹ focused on psycho-social support as part of MDT. The authors found out that in the initial phases of the multidisciplinary care psycho-social counselling is secondary to medical treatment. What is more psychologists rarely collaborate with medical professionals and the former take on reconciliatory role between medical professionals, patients and parents in the last stages of the care process.

Confidential: For Review Only

3. Models of collaboration & barriers

In most studies^{17–21 11–16} the model of collaboration – multidisciplinary, interdisciplinary or transdisciplinary - was not explicitly mentioned. Still most of the papers seemed to indicate a multidisciplinary approach in MDTs described as the simultaneous but independent contribution of two or more team members. Two empirical studies^{21 22} and the mixed methods study⁹ show that although participants referred to their team as a MDT or even interprofessional, their responses reflect a disintegrated approach.

In most studies, interaction among team members was mediated by a team coordinator who was responsible for delegating and reviewing tasks^{11–18,20}. The coordinator was usually one of the following specialists: endocrinologists^{11,16,18}, geneticists²⁰, a physician¹³, social worker¹⁵, or psychologist¹². Only in the study of Streuli and colleagues²¹ the MDT collaborated and cooperated with patients and parents without the mediation of a coordinator.

In most empirical^{17–21} and theoretical^{11–16} articles the model of collaboration was not explicitly mentioned but most of the papers seem to indicate that MDTs take a multidisciplinary approach insofar the teamwork was described as the simultaneous and independent contribution of two or more team members. Only the mixed methods study of Sanders and colleagues⁹ included an interprofessional team approach where patients, parents and members of the MDT actively cooperate in the treatment process in order to co-create knowledge and improve the care of people with VSC and help parents cope with their child's condition.

As Liao and Roen¹⁹ pointed out medical professionals have more important role than psychologists whose work is seen as non-intervention because it is not medical and it is as such often side-lined.

The most often mentioned barriers to multidisciplinary collaboration were lack of financial, organisational and financial resources at hospitals and care centres for MDTs to be implemented and registered^{11–14,18}. The key barrier to collaboration, e. g. formation of MDTs in these centres is the lack of specialists^{9,12,13,18}. One fourth of the papers^{9,12,21} stressed the absence of confidentiality between team members, patients and parents as a barrier to collaboration process because sharing information can be distressing to parents to the point where they cannot participate in the shared decision making process.

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Two papers ^{14,20} pointed out the difficulties of diagnosis referred to as the time of diagnosis and the precise determination of VSC. The lack of cooperation between medical professionals and psychologists and prevalence of medicalised approach was highlighted as a barrier in one case ¹⁹. Only one study ²¹ pointed out the emotional distancing and difficulties of medical professionals to distinguish facts from assumptions as obstacle to collaboration process. One fourth ^{15–17} of the papers did not specify any barriers to collaboration process.

4. Ethical principles of MDT teams

The most commonly cited ethical principles were informed consent ^{11,12,14,16}, and shared decision-making ^{13,15,17,18,20,21}. However, only a minority ^{9,11,12,17} of papers provided an account of implementation of these two ethical principles. The papers ^{9,11,12,17} stated that parents needed to be educated about the condition of their child and that parental fears need to be considered in the decision making process. Yet there was lack of mention of how patients themselves growing up should be educated about their condition and actively involved in the decision-making process. Only two papers mentioned the involvement of patients in the decision making process ^{11,15}. Two papers ^{13,20} emphasized that the communication between MDT and parents/patients in the process of making an ethical decision should be open and should include the concerns of parents, but not children.

Discussion

The scoping review identified 12 studies that either empirically or theoretically provided an account of multidisciplinary teams caring for patients with VSC. Almost all articles stressed the importance of MDT, but under closer examination the exact nature of collaboration remained unclear. The prevalent approach seemed to be multidisciplinary, that is, collaboration in which different care providers work simultaneously but separately. The papers rarely elaborated on implementation of multidisciplinary let alone critically examine it. Research on MDT in other healthcare contexts suggests that it is not enough to have a unit of different health care professionals working together ^{23,24}, but the responsibility, knowledge and authority should be flexibly shared and team members should believe in cooperation ^{23,25–27}. However, the studies in our scoping review failed to address these suggestions as there are no indicators to assess the impact of the MDT which could lead to improved care for people with VSC.

The teamwork is usually coordinated by an endocrinologist, physician, and in a few instances by a psychologist, even though this was not always empirically assessed, because the exact nature of the relationships with the teams and their working practices were not revealed. The papers clearly demonstrate the dominance of medical professionals over other healthcare experts and psychosocial care in the core teams which necessarily include endocrinologists, urologists, and surgeon and to lesser extent psychologists, social worker, and ethicist.

Our scoping review confirmed the findings that tendency toward a more medical-oriented structure (predominance of doctors in the teams) of multidisciplinary teams leads to poor collaboration and efficacy ^{27,28}.

This was also partly confirmed by data on psychological support which is thought of and provided in terms of “alleviating emotional distress of parents facing the fact that they have a child with VSC”. Psychological support is provided to mediate relations between families and medical professionals, but it seen as addition to the treatment provided by medical professionals.

The account of psychological support revealed absence of child-centred approach and a lack of combined child centred approach with family-oriented care as there was no mention of what kind psychological support is provided for people with VSC, but only for their families. This was reverberated in ethical principles as only two papers mentioned that the decision making process and informed consent should include people with VSC. This might be since the majority of papers focused on infants and children, however these studies failed to address the role and implementation of shared decision making for them. The studies also did not refer to care of adults and transition of care from adolescence to adulthood.

The lack of inclusion of patients’ perspective and preferences in the treatment of people with VSC and shared decision making process in the examined literature is consistent with previous findings. According to these findings health care professionals stated that patient’s perspectives should be an important part of the meetings of the MDT, but do not consider it beneficial to the meetings of MDTs ²⁸. It is seen to be at the odds with professionals standards, and what is more medical professionals conflate shared decision making process with informed consent or there is no awareness of the former term ²⁹.

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Although some papers aimed to advocate for approach according to which teams educate their patients and even learn from them – the interprofessional approach which seems to de-hierarchize the knowledge relations between patients and medical professionals – they remain a minority within the current literature on medical collaboration in multidisciplinary teams working with people with VSC ⁹.

Limitations

The scoping review explored the existing literature on MDTs examining the collaboration processes and ethical frameworks. Some relevant studies might have been overlooked due to exclusion/inclusion criteria, e. g. conference abstracts and grey literature might have provided information from patients on the MDTs. Nevertheless, our review provides an overview of the existing literature on collaboration of MDT caring for people with VSC and provides important directions for further research that will hopefully lead to better care of people with VSC. Therefore we propose the following suggestions for future research: investigating the role of the health care professionals in the teams in the decision making process; examining the nature of relationship between patients and MDTs; examining the lack of care for adults and transition; more research on how MDTs can actually work together; researching new models of collaboration within the MDTs and how they relate to ethical dilemmas working with people with VSC: informed consent vs. growing mental capabilities of children and their rights to participate in their treatment.

Conclusion

The scoping review revealed that teams caring for people with VSC are seemingly multidisciplinary. The collaboration among them lacks cooperation and synthesized discipline approach as one team member – usually a medical professional (an endocrinologist, a geneticist or a physician), rarely a psychologist or a social worker, coordinates the management process while the rest of the team members seem to work separately. Only a minority of team members come from disciplines such as social work or psychology. The most frequently cited ethical principles are shared decision making and informed consent, but both tend to focus on parents rather than on patients. Future studies should pursue empirical research on MDT by examining in the detail the process of shared decision making between MDT, parents, adults and children.

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Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?

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Title Page

Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?

A scoping literature review on the composition, collaboration, and ethical principles of multidisciplinary teams

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What is known:

Since the introduction of Chicago consensus statement multidisciplinary teams have been integrated in treatment of people with VSC. However, the implementation of MDTs in literature is unclear: there is no information on the composition of teams, collaboration processes and ethical framework.

What this study adds:

The study provides a literature overview on the collaboration and composition of MDTs. It fills the gap in the literature by showing that collaboration in MDTs is poor, that medical professionals dominate over other health care professionals, that psychosocial care is secondary to medical treatment and that ethical frameworks excluded the voices of people with VSC.

Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?

A scoping literature review on the composition, collaboration, and ethical principles of multidisciplinary teams

Abstract

Background

In 2006 the Chicago consensus statement on the management of people with variations of sex characteristics (VSC) acknowledged the importance of a multidisciplinary team (MDT) approach. The consensus update from 2016 reinforced the call for multidisciplinary collaborations between medical professionals, parents and support groups, and proposed guidelines to improve shared decision making and patient centered care embedded in ethical principles of self-determination and child participation. But there is little evidence that successfully multidisciplinary teams have been implemented in clinical practice.

Methods and aims

A scoping review was conducted to identify studies that address the collaboration and decision making process of multidisciplinary teams providing care of people with VSC to identify ideal and actual (1) team composition (2) models of collaboration and (3) ethical principles that MDT teams follow. Six databases were systematically searched: CINAHL, Medline, Psychinfo, Scopus, Socindex and Web of Science. No restriction was placed on the type of methodology used in the studies. To frame the research, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses was used.

Results

The MDT teams in the literature include mainly medical professionals: endocrinologists, urologists and surgeons. The collaboration among medical professionals in multidisciplinary teams lacks cooperation as one team member sets the tasks of the team while each professional works separately. Despite the importance of psycho-social support the involvement of psychologists remains secondary. The implementation of ethical principles tends to exclude people with VSC.

Conclusion

The care of people with VSC described in the papers is medically oriented as the team members are mainly medical professionals working separately. MDT tend to exclude people with VSC despite references to shared decision making processes and informed consent. There was no mention of adult care and lack of inclusion of patient's perspective in the care process. The future research should do more empirical research of MDTs.

Key words: multidisciplinary teams, shared decision making, people with variations of sex characteristics/differences of sex development (DSD), patient-centred care

Introduction

Variations of sex characteristics (VSC) demand a multidisciplinary care approach ¹, because human sex is determined by multiple factors ²: genetic, gonadal, hormonal, phenotypic, and psychological sex. The need to bring together a broad range of health care professionals to provide care for people with VSC has been recognized also by the Chicago consensus statement of 2006 ^{3,4}. The consensus statement has introduced new guidelines for the care of people with VSC and their families. These recommendations include: (1) the provision of long-term multidisciplinary care (including psycho-social support), open and on-going communication, the deferral of early cosmetic surgeries until the age of informed consent and the use of a new medical umbrella term DSD ^{3,5}. According to the consensus statement, multidisciplinary teams (MDT) are to include: (paediatric) endocrinologists, urologists, surgeons, psychiatrists/psychologists, gynaecologists, geneticists, neonatologists; and if available: social workers, nurses and medical ethicists ³. The MDT team should educate other health care professionals involved in the treatment of people with VSC, communicate with family members under supervision of a (health) care professional and develop a plan for clinical management ^{3,4,6}. Care should be patient-centered and focus on children's growing capabilities to participate in decisions regarding their health and thus pose a limit to parental authority ².

The updated consensus statement of 2016 seemed to recognize this important paradigm shift in children's rights by considering shared decision-making as "the crux of patient-centred care". Healthcare experts should share their knowledge but also their uncertainties in care and outcomes with patients and families and give them enough time and support to make fully informed decisions.

A crucial aspect of this patient-centered, individualized care approach is the endorsement by the Chicago consensus of healthcare teams that are composed of different provider types. Such teams can be multidisciplinary, interdisciplinary and transdisciplinary depending on the degree of collaboration⁴. The Chicago consensus does not specify which MDT would be the most appropriate. However the 2016 update defines types of collaboration in detail. In multidisciplinary teams two or more team members work simultaneously but separately; interdisciplinary teams involve the joint work of professionals from different disciplines sharing knowledge and skills to address a common problem and in transdisciplinary teams various disciplines are brought together to create new ways of solving problems and share responsibility of care⁴. Although Lee and colleagues⁴ explain the differences between these types of teams, they do not give any practical indications on how to set up such teams, nor do they explain which type of team is more suitable in which kind of context.

Studies suggest that regular MDT meetings may result in active deferral of early cosmetic surgeries⁷. On the one hand, data seems to suggest that the majority of teams in Europe accepts the MDT approach while other studies portray a less optimistic situation. Moreover, empirical data on the actual functioning of MDT, their collaboration with patients and families as well as their efficacy remain poorly documented^{8,9}. It is often unclear, in fact, who is actually included in the team, what the role of each team member is, how various healthcare professionals collaborate, how people with VSC and their families are involved in the decision-making process regarding their health and what impact MDT have on care management and patient well-being.

The following paper aims to critically examine the existing scientific literature on the composition of MDT in the care of people with VSC, to describe the implementation of multidisciplinary teams in the care of people with VSC.

For this purpose, the manuscript aims to identify ideal and actual (1) MDT composition; (2) models of collaboration and (3) ethical principles that guide MDT teams. It further aims to identify possible barriers to the adequate implementation of MDT and examine any assessments of their impact on the care of persons with VSC. Finally, the review aims to identify possible gaps in the existing research on MDT.

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Methods

Given the broad aim of the research question, a scoping review was conducted to provide an overview and critical analysis of the existing literature on MDT caring for people with VSC. We searched the following data bases: CINAHL, Medline, Psychinfo, Scopus, Socindex and Web of Science. The research terms were selected after discussions within the research team and extensive background reading on the topic (see Table 1). Inclusion criteria were: published in peer reviewed journals between 2006–2021, written in English, German or French. A 15-year publication window was chosen to capture all studies that were published after the publication of the Chicago consensus statement of 2006. In line with scoping reviews, no restriction was placed on they type of study (theoretical, intervention, quantitative, qualitative or mixed method) However, book chapters, literature reviews, expert reports, commentaries, conference abstracts and books were excluded. Given that in the medical community the acronym DSD is prevalent, we used it as a search term together with intersex. Terms such as “diverse sex development” and “variations of sex development” were not included in the search query because although these research terms are often relevant for affected persons and activists, they are not yet ingrained in the scientific literature and the preliminary searches gave no additional results when using these terms.

Table 1: Search query

Search terms	WoS	Scopus	Medline	CINAHL	Psychinfo	Socioindex
(intersex* OR "disorders of sex development" OR "differences of sex development" OR "genital ambiguity")	8,312	7,018	2,287	466	930	331
(child* OR minor* OR infant* OR newborn* OR baby OR babies OR paediatr* OR pediater* OR boy* OR girl* OR neonat* OR adolescent*)	4,111,869	2,875,699	1,258,637	523,079	541,804	132,823
(ethic* OR decision* OR issue* OR "decision making" OR "masculinizing surgery" OR "feminizing surgery" OR "genetic selection" OR "psychosocial support" OR "genital surgery" OR "surgical intervention" OR "hormone replacement therapy" OR standard* OR guidelines OR "best interest" OR harm* OR "human rights" OR autonom* OR assessment OR evaluation OR care OR medical management)	12,727,466	1,520,839	3,237,731	1,270,357	986,407	986,407
(multidisciplinary* OR interdisciplinary* OR interprofession* OR multilateral OR transdisciplinary* OR transprofession* OR holis*)	345,970	343,642	116,958	57,007	48,329	11,091
(intersex* OR "disorders of sex development" OR "differences of sex development" OR "genital ambiguity") AND (child* OR minor* OR infant* OR newborn* OR baby OR babies OR paediatr* OR pediater* OR boy* OR girl* OR neonat* OR adolescent*) AND (ethic* OR decision* OR issue* OR "decision making" OR "masculinizing surgery" OR "feminizing surgery" OR "genetic selection" OR "psychosocial support" OR "genital surgery" OR "surgical intervention" OR "hormone replacement therapy" OR standard* OR guidelines OR "best interest" OR harm* OR "human rights" OR autonom* OR assessment OR evaluation OR care OR medical management) AND (multidisciplinary* OR interdisciplinary* OR interprofession* OR multilateral OR transdisciplinary* OR transprofession* OR holis*)	189	102	82	26	14	2

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We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines ¹⁰ (see Figure 1). The combined research of 6 databases gave 415 results and 1 article was added through other sources. After deduplicating (using Zotero) 251 units remained and were further screened on the basis of title and abstract. The articles that referred to intersex or DSD, but did not refer to MDT were excluded. The screening process of the first author was checked and unified with the second author, who confirmed which articles were eligible based on the abstract. The first screening gave 35 results. After that the references of the already selected studies were checked to identify additional studies. This resulted in a final sample of 37 units. In the next step, the first and second author then read the full text versions of these articles. 25 records were excluded because they only loosely referred to MDT and either (1) failed to list which healthcare professionals are part of MDT; (2) made not reference to MDT collaboration models; (3) almost exclusively focused on the clinical management or psycho-social care of people with VSC; (4) or discussed the role of only one MDT member, without any description of their collaboration with other team members.

Figure 1: Search process using PRISMA Systematic Review of Literature

The data from the selected 12 articles was extracted by making a Microsoft Excel spreadsheet, secured and available to all team members. The spreadsheet included sections for authors name, year of publication, country of origin, name of the journal, study design, data analysis, key findings, patient age cohort, intersex variation, medical management, psychosocial care, composition of the team, approaches to collaboration, conceptual issues, ethical framework.

Patient and Public Involvement statement

No patients were involved in conducting this study.

Results

1. General characteristics of included studies

Out of the final 12 articles 6 were theoretical ¹¹⁻¹⁶, 5 were empirical ¹⁷⁻²¹ and 1 was a mixed methods study ⁹. One third (4) of the articles were published in the UK ^{9,11,12,18}, the other third in the USA ^{13,15,17,20} and the remaining third came from Switzerland and Germany ²¹, Sweden and UK ¹⁹, Australia ¹⁶ and Germany ¹⁴ (see Table 2 and Table 3).

Table 2: included theoretical studies

Author	Year	Country	Study design	Patient cohort	Psychosocial care	Composition of team	Approaches to collaboration	Conceptual issues	Ethical framework
Ahmed et. al.	2016	UK	theoretical	adolescents	Clinical psychologist should examine early emotions of people with VSC, facilitate adjustment of parents to new-born, informed decision-making process.	endocrinologist, surgeon and/or urologist, clinical psychologist/psychiatrist, radiologist, nurse and neonatologist.	Paediatric endocrinologist should take the role of coordinator of sex assignment and decision-making process.	multidisciplinary	informed consent
Brain et. al.	2010	UK	theoretical	new-borns	Psychologist as mediator between physicians and patients	endocrinologist, (paediatric) urologist/surgeon, gynaecologist, psychologist, biochemist, clinical/molecular geneticist, ethicist	Psychologist has the crucial role, manages the process of communication between physicians and families	multidisciplinary	Informed consent and decision making
Gomez Lobo	2014	USA	theoretical	infants, children, adolescents	Psychosocial support should cover family support and facilitation of the decision-making process regarding medical treatment.	Physician, endocrinologist, nurse, counsellors, geneticist, paediatric urologist, surgeon, radiologist, bioethicist, gynaecologist - focus in this article.	A team coordinator is important in the creation of the service as well as ongoing functioning of the team and the team should educate other health care professionals	multidisciplinary	Shared decision making
Hiort et. al.	2014	D	theoretical	infants, children	/	endocrinologist, surgeon/urologist, psychologist, gynaecologist, geneticist, molecular biologist, radiologist, pathologist, biochemist.	Patient navigator coordinates communication between patients/families with the team.	multidisciplinary	informed consent
Moran and Karkazis	2012	USA	theoretical	infants, children	psychiatrist, and/or social worker can provide early and ongoing psychosocial care and access to support resources for parents and patients.	paediatric endocrinologist, a paediatric urologist and/or surgeon, and a psychologist, psychiatrist, and/or social worker	The development of a team requires coordination in the planning, implementation, and functioning stages, and a team coordinator.	multidisciplinary	shared decision making.

Vora and Srinivasan	2010	AU	theoretical	neonates, children, adolescents	The (clinical) psychologist can aid in assessing the parents' and young person's understanding of information discussed and provide family support in a culturally sensitive manner.	endocrinologist, urologist, gynaecologist	The biomedical assessment is most often coordinated by the paediatric endocrinologist.	multidisciplinary	Informed consent?
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Table 3: included empirical studies

Author	Year	Country	Study design	Patient cohort	Psychosocial care	Composition of team	Approaches to collaboration	Conceptual issues	Ethical framework
Chawla et. al.	2019	USA	empirical	an infant	Psychosocial support was provided: risk and benefits including the psychological consequences of having atypical genitalia were reviewed with the family.	endocrinologist, urologist, and paediatric, surgeon, clinical coordinator	clinical professional coordinates the team and shared decision-making process	multidisciplinary	Shared decision making
Kyriakou et. al.	2016	UK	empirical	children	/	paediatric endocrinologist, clinical geneticist, paediatrician, neonatologist, adult endocrinologist	Paediatric endocrinologist has the central role in the team.	multidisciplinary	Informed consent
Liao and Roen	2019	UK, SE	empirical	children	Psychologists' role is pushed aside in the begging of examination. The psychologist sometimes mediates the emotional mess to prevent patients from disengaging with the service.	gynaecologists, urologists, paediatric surgeons, endocrinologists, geneticists, psychologists, and nurse specialists.	Team means a collection of specialists - there is no real collaboration, it is rather multi-professional.	multidisciplinary	/
Parisi et. al.	2007	USA	empirical	infants, children	Psychosocial support for families: parents are given pragmatic, age-appropriate recommendations for disclosure of a diagnosis of a DSD to a child in an honest, non-stigmatizing manner.	specialists in medical genetics, cytogenetics, gynaecology, and reproductive endocrinology and the paediatric specialties of urology, endocrinology, adolescent medicine, and psychiatry.	The role of geneticists is highlighted and in the initial stages coordinates the team.	multidisciplinary	shared decision making
Sanders et. al.	2017	UK	mixed method	children, adolescents	The nurse and psychologists are information exchange agents acting in an advocacy role.	Endocrinologist and geneticist were always present. In nine out of 10 clinics urologist and psychologist. Gynaecologists were present in seven clinics, nurse attended three clinics, one site had a nurse as a consistent and integral member of the team.	Patients are also educators: general discussions about which topics or concerns were likely to be raised in clinic as issues based on connection to families helped professionals to "really think about what's	interprofessional	/

							going to happen in a consultation.”		
Streuli et. al	2012	CH, D	empirical	children	Psychosocial care is shared and provided or at least considered by all MDTs.	Paediatric endocrinologist, psychologist, specialist in sexual medicine, child and adolescent psychiatrist, paediatric surgeon, social worker, study nurse, gynaecologist, neonatologist, member of a support group	The team members collaborate with each other, family and the patient.	interprofessional (only pro forma), in reality it is multidisciplinary	shared and information based decision making process

Only two empirical studies ^{17,18} addressed MDT in relation to a specific VSC: CAH and 46, XY DSD. Other studies either referred to a wide array of VSC: ^{11–14,20} or provided no specification ^{9,15,16,19,21} (see Table 2).

The majority of studies discussed MDTs in relation to infants and children ^{12–15,17–21}. Two studies referred to children and adolescents ^{9,16} and only one focused exclusively on adolescents ¹¹. Overall the focus on adolescents was limited and none of the papers discussed MDT in relationship to adults (see Table 2).

Except for ^{17,19} most studies referred to VSC in terms of disorders/differences of sex development and used the acronym without any critical reflection or explanation of it ^{9,11–16,18,20,21}. Two papers explicitly referred to VSC as a pathology ^{11,16}.

2. The ideal and actual composition of MDT.

According to most theoretical studies MDT ideally consist of an endocrinologist, an urologist, and a surgeon ^{11–16}. Some papers also include geneticists ^{11–14}, psychologists ^{11–15}, gynaecologists ^{12–14,16} and radiologists ^{11,13,14}.

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However in practice, the core team was composed of endocrinologists ^{9,17-21}, accompanied almost always by urologists/surgeons ^{9,17,19-21}, geneticists ^{9,18-20}, gynaecologists ^{9,19-21} and psychologist/psychiatrists ^{9,19-21}.

The vast majority of articles considered multiple methods of medical management as being the task of MDTs: genetic testing (including karyotyping), biomedical assessment (such as hormone levels, blood and urine tests), genital surgery and ultrasounds ^{11-14,16-21}. Less than half of the papers suggest that in the MDTs each specialist is singularly responsible for the medical management ^{11-14,17}. Half of the papers did not specify the responsibility for medical management ^{9,16,18-21}. Only one paper ¹⁵ argued that specialists should talk to each other about their medical tasks and collaborate with coordinator.

Next to medical management, psychosocial care was considered by 6 articles to be a key task of MDT. This role was mostly ascribed to psychologists ^{9,11-13,16,19}. In only one paper psychosocial care was said to be provided by all the members of the team ²¹.

Most studies focused on the importance of psychosocial support for parents to help them cope with their child being intersex ^{11,13,16}. Psychologists should provide them information, connect parents them to support groups ^{13,16} and function as mediators between parents and health care professionals to facilitate the decision-making process ^{12,13}. Ahmed and colleagues ¹¹ argued that psychosocial support ought to be provided to people with VSC in general to help them cope with the whole process. Only one empirical study ¹⁹ focused on psycho-social support as part of MDT. The authors found out that in the initial phases of the multidisciplinary care psycho-social counselling is secondary to medical treatment. What is more psychologists rarely collaborate with medical professionals and the former take on reconciliatory role between medical professionals, patients and parents in the last stages of the care process.

3. Models of collaboration & barriers

In most studies^{17–21 11–16} the model of collaboration – multidisciplinary, interdisciplinary or transdisciplinary - was not explicitly mentioned. Still most of the papers seemed to indicate a multidisciplinary approach in MDTs described as the simultaneous but independent contribution of two or more team members. Two empirical studies^{21 22} and the mixed methods study⁹ show that although participants referred to their team as a MDT or even interprofessional, their responses reflect a disintegrated approach.

In most studies, interaction among team members was mediated by a team coordinator who was responsible for delegating and reviewing tasks^{11–18,20}. The coordinator was usually one of the following specialists: endocrinologists^{11,16,18}, geneticists²⁰, a physician¹³, social worker¹⁵, or psychologist¹². Only in the study of Streuli and colleagues²¹ the MDT collaborated and cooperated with patients and parents without the mediation of a coordinator.

In most empirical^{17–21} and theoretical^{11–16} articles the model of collaboration was not explicitly mentioned but most of the papers seem to indicate that MDTs take a multidisciplinary approach insofar the teamwork was described as the simultaneous and independent contribution of two or more team members. Only the mixed methods study of Sanders and colleagues⁹ included an interprofessional team approach where patients, parents and members of the MDT actively cooperate in the treatment process in order to co-create knowledge and improve the care of people with VSC and help parents cope with their child's condition.

As Liao and Roen¹⁹ pointed out medical professionals have more important role than psychologists whose work is seen as non-intervention because it is not medical and it is as such often side-lined.

The most often mentioned barriers to multidisciplinary collaboration were lack of financial, organisational and financial resources at hospitals and care centres for MDTs to be implemented and registered^{11–14,18}. The key barrier to collaboration, e. g. formation of MDTs in these centres is the lack of specialists^{9,12,13,18}. One fourth of the papers^{9,12,21} stressed the absence of confidentiality between team members, patients and parents as a barrier to collaboration process because sharing information can be distressing to parents to the point where they cannot participate in the shared decision making process.

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Two papers ^{14,20} pointed out the difficulties of diagnosis referred to as the time of diagnosis and the precise determination of VSC. The lack of cooperation between medical professionals and psychologists and prevalence of medicalised approach was highlighted as a barrier in one case ¹⁹. Only one study ²¹ pointed out the emotional distancing and difficulties of medical professionals to distinguish facts from assumptions as obstacle to collaboration process. One fourth ¹⁵⁻¹⁷ of the papers did not specify any barriers to collaboration process.

4. Ethical principles of MDT teams

The most commonly cited ethical principles were informed consent ^{11,12,14,16}, and shared decision-making ^{13,15,17,18,20,21}. However, only a minority ^{9,11,12,17} of papers provided an account of implementation of these two ethical principles. The papers ^{9,11,12,17} stated that parents needed to be educated about the condition of their child and that parental fears need to be considered in the decision making process. Yet there was lack of mention of how patients themselves growing up should be educated about their condition and actively involved in the decision-making process. Only two papers mentioned the involvement of patients in the decision making process ^{11,15}. Two papers ^{13,20} emphasized that the communication between MDT and parents/patients in the process of making an ethical decision should be open and should include the concerns of parents, but not children.

Discussion

The scoping review identified 12 studies that either empirically or theoretically provided an account of multidisciplinary teams caring for patients with VSC. Almost all articles stressed the importance of MDT, but under closer examination the exact nature of collaboration remained unclear. The prevalent approach seemed to be multidisciplinary, that is, collaboration in which different care providers work simultaneously but separately. The papers rarely elaborated on implementation of multidisciplinary let alone critically examine it. Research on MDT in other healthcare contexts suggests that it is not enough to have a unit of different health care professionals working together ^{23,24}, but the responsibility, knowledge and authority should be flexibly shared and team members should believe in cooperation ^{23,25-27}. However, the studies in our scoping review failed to address these suggestions as there are no indicators to assess the impact of the MDT which could lead to improved care for people with VSC.

The teamwork is usually coordinated by an endocrinologist, physician, and in a few instances by a psychologist, even though this was not always empirically assessed, because the exact nature of the relationships with the teams and their working practices were not revealed. The papers clearly demonstrate the dominance of medical professionals over other healthcare experts and psychosocial care in the core teams which necessarily include endocrinologists, urologists, and surgeon and to lesser extent psychologists, social worker, and ethicist.

Our scoping review confirmed the findings that tendency toward a more medical-oriented structure (predominance of doctors in the teams) of multidisciplinary teams leads to poor collaboration and efficacy ^{27,28}.

This was also partly confirmed by data on psychological support which is thought of and provided in terms of “alleviating emotional distress of parents facing the fact that they have a child with VSC”. Psychological support is provided to mediate relations between families and medical professionals, but it seen as addition to the treatment provided by medical professionals.

The account of psychological support revealed absence of child-centred approach and a lack of combined child centred approach with family-oriented care as there was no mention of what kind psychological support is provided for people with VSC, but only for their families. This was reverberated in ethical principles as only two papers mentioned that the decision making process and informed consent should include people with VSC. This might be since the majority of papers focused on infants and children, however these studies failed to address the role and implementation of shared decision making for them. The studies also did not refer to care of adults and transition of care from adolescence to adulthood.

The lack of inclusion of patients’ perspective and preferences in the treatment of people with VSC and shared decision making process in the examined literature is consistent with previous findings. According to these findings health care professionals stated that patient’s perspectives should be an important part of the meetings of the MDT, but do not consider it beneficial to the meetings of MDTs ²⁸. It is seen to be at the odds with professionals standards, and what is more medical professionals conflate shared decision making process with informed consent or there is no awareness of the former term ²⁹.

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Although some papers aimed to advocate for approach according to which teams educate their patients and even learn from them – the interprofessional approach which seems to de-hierarchize the knowledge relations between patients and medical professionals – they remain a minority within the current literature on medical collaboration in multidisciplinary teams working with people with VSC ⁹.

Limitations

The scoping review explored the existing literature on MDTs examining the collaboration processes and ethical frameworks. Some relevant studies might have been overlooked due to exclusion/inclusion criteria, e. g. conference abstracts and grey literature might have provided information from patients on the MDTs. Nevertheless, our review provides an overview of the existing literature on collaboration of MDT caring for people with VSC and provides important directions for further research that will hopefully lead to better care of people with VSC. Therefore we propose the following suggestions for future research: investigating the role of the health care professionals in the teams in the decision making process; examining the nature of relationship between patients and MDTs; examining the lack of care for adults and transition; more research on how MDTs can actually work together; researching new models of collaboration within the MDTs and how they relate to ethical dilemmas working with people with VSC: informed consent vs. competence and capacity of children and young people of children and their rights to participate in their treatment.

Conclusion

The scoping review revealed that teams caring for people with VSC are seemingly multidisciplinary. The collaboration among them lacks cooperation and synthesized discipline approach as one team member – usually a medical professional (an endocrinologist, a geneticist or a physician), rarely a psychologist or a social worker, coordinates the management process while the rest of the team members seem to work separately. Only a minority of team members come from disciplines such as social work or psychology. The most frequently cited ethical principles are shared decision making and informed consent, but both tend to focus on parents rather than on patients. Future studies should pursue empirical research on MDT by examining in the detail the process of shared decision making between MDT, parents, adults and children.

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Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?

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Title Page

Multidisciplinary teams caring for people with variations of sex characteristics: a scoping review

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What is known:

Since the introduction of Chicago consensus statement multidisciplinary teams have been integrated in treatment of people with VSC. However, the implementation of MDTs in literature is unclear: there is no information on the composition of teams, collaboration processes and ethical framework.

What this study adds:

The study provides a literature overview on the collaboration and composition of MDTs. It fills the gap in the literature by showing that collaboration in MDTs is poor, that medical professionals dominate over other health care professionals, that psychosocial care is secondary to medical treatment and that ethical frameworks excluded the voices of people with VSC.

Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?

A scoping literature review on the composition, collaboration, and ethical principles of multidisciplinary teams

Abstract

Background

In 2006 the Chicago consensus statement on the management of people with variations of sex characteristics (VSC) acknowledged the importance of a multidisciplinary team (MDT) approach. The consensus update from 2016 reinforced the call for multidisciplinary collaborations between medical professionals, parents and support groups, and proposed guidelines to improve shared decision making and patient centered care embedded in ethical principles of self-determination and child participation. But there is little evidence that successfully multidisciplinary teams have been implemented in clinical practice.

Methods and aims

A scoping review was conducted to identify studies that address the collaboration and decision making process of multidisciplinary teams providing care of people with VSC to identify ideal and actual (1) team composition (2) models of collaboration and (3) ethical principles that MDT teams follow. Six databases were systematically searched: CINAHL, Medline, Psychinfo, Scopus, Socindex and Web of Science. No restriction was placed on the type of methodology used in the studies. To frame the research, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses was used.

Results

The MDT teams in the literature include mainly medical professionals: endocrinologists, urologists and surgeons. The collaboration among medical professionals in multidisciplinary teams lacks cooperation as one team member sets the tasks of the team while each professional works separately. Despite the importance of psycho-social support the involvement of psychologists remains secondary. The implementation of ethical principles tends to exclude people with VSC.

Conclusion

The care of people with VSC described in the papers is medically oriented as the team members are mainly medical professionals working separately. MDT tend to exclude people with VSC despite references to shared decision making processes and informed consent. There was no mention of adult care and lack of inclusion of patient's perspective in the care process. The future research should do more empirical research of MDTs.

Key words: multidisciplinary teams, shared decision making, people with variations of sex characteristics/differences of sex development (DSD), patient-centred care

Introduction

Variations of sex characteristics (VSC) demand a multidisciplinary care approach ¹, because human sex is determined by multiple factors ²: genetic, gonadal, hormonal, phenotypic, and psychological sex. The need to bring together a broad range of health care professionals to provide care for people with VSC has been recognized also by the Chicago consensus statement of 2006 ^{3,4}. The consensus statement has introduced new guidelines for the care of people with VSC and their families. These recommendations include: (1) the provision of long-term multidisciplinary care (including psycho-social support), open and on-going communication, the deferral of early cosmetic surgeries until the age of informed consent and the use of a new medical umbrella term DSD ^{3,5}. According to the consensus statement, multidisciplinary teams (MDT) are to include: (paediatric) endocrinologists, urologists, surgeons, psychiatrists/psychologists, gynaecologists, geneticists, neonatologists; and if available: social workers, nurses and medical ethicists ³. The MDT team should educate other health care professionals involved in the treatment of people with VSC, communicate with family members under supervision of a (health) care professional and develop a plan for clinical management ^{3,4,6}. Care should be patient-centered and focus on children's growing capabilities to participate in decisions regarding their health and thus pose a limit to parental authority ².

The updated consensus statement of 2016 seemed to recognize this important paradigm shift in children's rights by considering shared decision-making as "the crux of patient-centred care". Healthcare experts should share their knowledge but also their uncertainties in care and outcomes with patients and families and give them enough time and support to make fully informed decisions.

A crucial aspect of this patient-centered, individualized care approach is the endorsement by the Chicago consensus of healthcare teams that are composed of different provider types. Such teams can be multidisciplinary, interdisciplinary and transdisciplinary depending on the degree of collaboration⁴. The Chicago consensus does not specify which MDT would be the most appropriate. However the 2016 update defines types of collaboration in detail. In multidisciplinary teams two or more team members work simultaneously but separately; interdisciplinary teams involve the joint work of professionals from different disciplines sharing knowledge and skills to address a common problem and in transdisciplinary teams various disciplines are brought together to create new ways of solving problems and share responsibility of care⁴. Although Lee and colleagues⁴ explain the differences between these types of teams, they do not give any practical indications on how to set up such teams, nor do they explain which type of team is more suitable in which kind of context.

Studies suggest that regular MDT meetings may result in active deferral of early cosmetic surgeries⁷. On the one hand, data seems to suggest that the majority of teams in Europe accepts the MDT approach while other studies portray a less optimistic situation. Moreover, empirical data on the actual functioning of MDT, their collaboration with patients and families as well as their efficacy remain poorly documented^{8,9}. It is often unclear, in fact, who is actually included in the team, what the role of each team member is, how various healthcare professionals collaborate, how people with VSC and their families are involved in the decision-making process regarding their health and what impact MDT have on care management and patient well-being.

The following paper aims to critically examine the existing scientific literature on the composition of MDT in the care of people with VSC, to describe the implementation of multidisciplinary teams in the care of people with VSC.

For this purpose, the manuscript aims to identify ideal and actual (1) MDT composition; (2) models of collaboration and (3) ethical principles that guide MDT teams. It further aims to identify possible barriers to the adequate implementation of MDT and examine any assessments of their impact on the care of persons with VSC. Finally, the review aims to identify possible gaps in the existing research on MDT.

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Methods

Given the broad aim of the research question, a scoping review was conducted to provide an overview and critical analysis of the existing literature on MDT caring for people with VSC. We searched the following data bases: CINAHL, Medline, Psychinfo, Scopus, Socindex and Web of Science. The research terms were selected after discussions within the research team and extensive background reading on the topic (see Table 1). Inclusion criteria were: published in peer reviewed journals between 2006–2021, written in English, German or French. A 15-year publication window was chosen to capture all studies that were published after the publication of the Chicago consensus statement of 2006. In line with scoping reviews, no restriction was placed on they type of study (theoretical, intervention, quantitative, qualitative or mixed method) However, book chapters, literature reviews, expert reports, commentaries, conference abstracts and books were excluded. Given that in the medical community the acronym DSD is prevalent, we used it as a search term together with intersex. Terms such as “diverse sex development” and “variations of sex development” were not included in the search query because although these research terms are often relevant for affected persons and activists, they are not yet ingrained in the scientific literature and the preliminary searches gave no additional results when using these terms.

Table 1: Search query

Search terms	WoS	Scopus	Medline	CINAHL	Psychinfo	Socioindex
(intersex* OR "disorders of sex development" OR "differences of sex development" OR "genital ambiguity")	8,312	7,018	2,287	466	930	331
(child* OR minor* OR infant* OR newborn* OR baby OR babies OR paediatr* OR pediater* OR boy* OR girl* OR neonat* OR adolescent*)	4,111,869	2,875,699	1,258,637	523,079	541,804	132,823
(ethic* OR decision* OR issue* OR "decision making" OR "masculinizing surgery" OR "feminizing surgery" OR "genetic selection" OR "psychosocial support" OR "genital surgery" OR "surgical intervention" OR "hormone replacement therapy" OR standard* OR guidelines OR "best interest" OR harm* OR "human rights" OR autonom* OR assessment OR evaluation OR care OR medical management)	12,727,466	1,520,839	3,237,731	1,270,357	986,407	986,407
(multidisciplinary* OR interdisciplinary* OR interprofession* OR multilateral OR transdisciplinary* OR transprofession* OR holis*)	345,970	343,642	116,958	57,007	48,329	11,091
(intersex* OR "disorders of sex development" OR "differences of sex development" OR "genital ambiguity") AND (child* OR minor* OR infant* OR newborn* OR baby OR babies OR paediatr* OR pediater* OR boy* OR girl* OR neonat* OR adolescent*) AND (ethic* OR decision* OR issue* OR "decision making" OR "masculinizing surgery" OR "feminizing surgery" OR "genetic selection" OR "psychosocial support" OR "genital surgery" OR "surgical intervention" OR "hormone replacement therapy" OR standard* OR guidelines OR "best interest" OR harm* OR "human rights" OR autonom* OR assessment OR evaluation OR care OR medical management) AND (multidisciplinary* OR interdisciplinary* OR interprofession* OR multilateral OR transdisciplinary* OR transprofession* OR holis*)	189	102	82	26	14	2

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We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines ¹⁰ (see Figure 1). The combined research of 6 databases gave 415 results and 1 article was added through other sources. After deduplicating (using Zotero) 251 units remained and were further screened on the basis of title and abstract. The articles that referred to intersex or DSD, but did not refer to MDT were excluded. The screening process of the first author was checked and unified with the second author, who confirmed which articles were eligible based on the abstract. The first screening gave 35 results. After that the references of the already selected studies were checked to identify additional studies. This resulted in a final sample of 37 units. In the next step, the first and second author then read the full text versions of these articles. 25 records were excluded because they only loosely referred to MDT and either (1) failed to list which healthcare professionals are part of MDT; (2) made not reference to MDT collaboration models; (3) almost exclusively focused on the clinical management or psycho-social care of people with VSC; (4) or discussed the role of only one MDT member, without any description of their collaboration with other team members.

Figure 1: Search process using PRISMA Systematic Review of Literature

The data from the selected 12 articles was extracted by making a Microsoft Excel spreadsheet, secured and available to all team members. The spreadsheet included sections for authors name, year of publication, country of origin, name of the journal, study design, data analysis, key findings, patient age cohort, intersex variation, medical management, psychosocial care, composition of the team, approaches to collaboration, conceptual issues, ethical framework.

Patient and Public Involvement statement

No patients were involved in conducting this study.

Results

1. General characteristics of included studies

Out of the final 12 articles 6 were theoretical ^{11–16}, 5 were empirical ^{17–21} and 1 was a mixed methods study ⁹. One third (4) of the articles were published in the UK ^{9,11,12,18}, the other third in the USA ^{13,15,17,20} and the remaining third came from Switzerland and Germany ²¹, Sweden and UK ¹⁹, Australia ¹⁶ and Germany ¹⁴ (see Table 2 and Table 3).

Table 2: included theoretical studies

Author	Year	Country	Study design	Patient cohort	Psychosocial care	Composition of team	Approaches to collaboration	Conceptual issues	Ethical framework
Ahmed et. al.	2016	UK	theoretical	adolescents	Clinical psychologist should examine early emotions of people with VSC, facilitate adjustment of parents to new-born, informed decision-making process.	endocrinologist, surgeon and/or urologist, clinical psychologist/psychiatrist, radiologist, nurse and neonatologist.	Paediatric endocrinologist should take the role of coordinator of sex assignment and decision-making process.	multidisciplinary	informed consent
Brain et. al.	2010	UK	theoretical	new-borns	Psychologist as mediator between physicians and patients	endocrinologist, (paediatric) urologist/surgeon, gynaecologist, psychologist, biochemist, clinical/molecular geneticist, ethicist	Psychologist has the crucial role, manages the process of communication between physicians and families	multidisciplinary	Informed consent and decision making
Gomez Lobo	2014	USA	theoretical	infants, children, adolescents	Psychosocial support should cover family support and facilitation of the decision-making process regarding medical treatment.	Physician, endocrinologist, nurse, counsellors, geneticist, paediatric urologist, surgeon, radiologist, bioethicist, gynaecologist - focus in this article.	A team coordinator is important in the creation of the service as well as ongoing functioning of the team and the team should educate other health care professionals	multidisciplinary	Shared decision making
Hiort et. al.	2014	D	theoretical	infants, children	/	endocrinologist, surgeon/urologist, psychologist, gynaecologist, geneticist, molecular biologist, radiologist, pathologist, biochemist.	Patient navigator coordinates communication between patients/families with the team.	multidisciplinary	informed consent
Moran and Karkazis	2012	USA	theoretical	infants, children	psychiatrist, and/or social worker can provide early and ongoing psychosocial care and access to support resources for parents and patients.	paediatric endocrinologist, a paediatric urologist and/or surgeon, and a psychologist, psychiatrist, and/or social worker	The development of a team requires coordination in the planning, implementation, and functioning stages, and a team coordinator.	multidisciplinary	shared decision making.

Vora and Srinivasan	2010	AU	theoretical	neonates, children, adolescents	The (clinical) psychologist can aid in assessing the parents' and young person's understanding of information discussed and provide family support in a culturally sensitive manner.	endocrinologist, urologist, gynaecologist	The biomedical assessment is most often coordinated by the paediatric endocrinologist.	multidisciplinary	Informed consent?
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Table 3: included empirical studies

Author	Year	Country	Study design	Patient cohort	Psychosocial care	Composition of team	Approaches to collaboration	Conceptual issues	Ethical framework
Chawla et. al.	2019	USA	empirical	an infant	Psychosocial support was provided: risk and benefits including the psychological consequences of having atypical genitalia were reviewed with the family.	endocrinologist, urologist, and paediatric, surgeon, clinical coordinator	clinical professional coordinates the team and shared decision-making process	multidisciplinary	Shared decision making
Kyriakou et. al.	2016	UK	empirical	children	/	paediatric endocrinologist, clinical geneticist, paediatrician, neonatologist, adult endocrinologist	Paediatric endocrinologist has the central role in the team.	multidisciplinary	Informed consent
Liao and Roen	2019	UK, SE	empirical	children	Psychologists' role is pushed aside in the begging of examination. The psychologist sometimes mediates the emotional mess to prevent patients from disengaging with the service.	gynaecologists, urologists, paediatric surgeons, endocrinologists, geneticists, psychologists, and nurse specialists.	Team means a collection of specialists - there is no real collaboration, it is rather multi-professional.	multidisciplinary	/
Parisi et. al.	2007	USA	empirical	infants, children	Psychosocial support for families: parents are given pragmatic, age-appropriate recommendations for disclosure of a diagnosis of a DSD to a child in an honest, non-stigmatizing manner.	specialists in medical genetics, cytogenetics, gynaecology, and reproductive endocrinology and the paediatric specialties of urology, endocrinology, adolescent medicine, and psychiatry.	The role of geneticists is highlighted and in the initial stages coordinates the team.	multidisciplinary	shared decision making
Sanders et. al.	2017	UK	mixed method	children, adolescents	The nurse and psychologists are information exchange agents acting in an advocacy role.	Endocrinologist and geneticist were always present. In nine out of 10 clinics urologist and psychologist. Gynaecologists were present in seven clinics, nurse attended three clinics, one site had a nurse as a consistent and integral member of the team.	Patients are also educators: general discussions about which topics or concerns were likely to be raised in clinic as issues based on connection to families helped professionals to "really think about what's	interprofessional	/

							going to happen in a consultation.”		
Streuli et. al	2012	CH, D	empirical	children	Psychosocial care is shared and provided or at least considered by all MDTs.	Paediatric endocrinologist, psychologist, specialist in sexual medicine, child and adolescent psychiatrist, paediatric surgeon, social worker, study nurse, gynaecologist, neonatologist, member of a support group	The team members collaborate with each other, family and the patient.	interprofessional (only pro forma), in reality it is multidisciplinary	shared and information based decision making process

Only two empirical studies ^{17,18} addressed MDT in relation to a specific VSC: CAH and 46, XY DSD. Other studies either referred to a wide array of VSC: ^{11–14,20} or provided no specification ^{9,15,16,19,21} (see Table 2).

The majority of studies discussed MDTs in relation to infants and children ^{12–15,17–21}. Two studies referred to children and adolescents ^{9,16} and only one focused exclusively on adolescents ¹¹. Overall the focus on adolescents was limited and none of the papers discussed MDT in relationship to adults (see Table 2).

Except for ^{17,19} most studies referred to VSC in terms of disorders/differences of sex development and used the acronym without any critical reflection or explanation of it ^{9,11–16,18,20,21}. Two papers explicitly referred to VSC as a pathology ^{11,16}.

2. The ideal and actual composition of MDT.

According to most theoretical studies MDT ideally consist of an endocrinologist, an urologist, and a surgeon ^{11–16}. Some papers also include geneticists ^{11–14}, psychologists ^{11–15}, gynaecologists ^{12–14,16} and radiologists ^{11,13,14}.

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However in practice, the core team was composed of endocrinologists ^{9,17-21}, accompanied almost always by urologists/surgeons ^{9,17,19-21}, geneticists ^{9,18-20}, gynaecologists ^{9,19-21} and psychologist/psychiatrists ^{9,19-21}.

The vast majority of articles considered multiple methods of medical management as being the task of MDTs: genetic testing (including karyotyping), biomedical assessment (such as hormone levels, blood and urine tests), genital surgery and ultrasounds ^{11-14,16-21}. Less than half of the papers suggest that in the MDTs each specialist is singularly responsible for the medical management ^{11-14,17}. Half of the papers did not specify the responsibility for medical management ^{9,16,18-21}. Only one paper ¹⁵ argued that specialists should talk to each other about their medical tasks and collaborate with coordinator.

Next to medical management, psychosocial care was considered by 6 articles to be a key task of MDT. This role was mostly ascribed to psychologists ^{9,11-13,16,19}. In only one paper psychosocial care was said to be provided by all the members of the team ²¹.

Most studies focused on the importance of psychosocial support for parents to help them cope with their child being intersex ^{11,13,16}. Psychologists should provide them information, connect parents them to support groups ^{13,16} and function as mediators between parents and health care professionals to facilitate the decision-making process ^{12,13}. Ahmed and colleagues ¹¹ argued that psychosocial support ought to be provided to people with VSC in general to help them cope with the whole process. Only one empirical study ¹⁹ focused on psycho-social support as part of MDT. The authors found out that in the initial phases of the multidisciplinary care psycho-social counselling is secondary to medical treatment. What is more psychologists rarely collaborate with medical professionals and the former take on reconciliatory role between medical professionals, patients and parents in the last stages of the care process.

3. Models of collaboration & barriers

In most studies^{17–21 11–16} the model of collaboration – multidisciplinary, interdisciplinary or transdisciplinary - was not explicitly mentioned. Still most of the papers seemed to indicate a multidisciplinary approach in MDTs described as the simultaneous but independent contribution of two or more team members. Two empirical studies^{21 22} and the mixed methods study⁹ show that although participants referred to their team as a MDT or even interprofessional, their responses reflect a disintegrated approach.

In most studies, interaction among team members was mediated by a team coordinator who was responsible for delegating and reviewing tasks^{11–18,20}. The coordinator was usually one of the following specialists: endocrinologists^{11,16,18}, geneticists²⁰, a physician¹³, social worker¹⁵, or psychologist¹². Only in the study of Streuli and colleagues²¹ the MDT collaborated and cooperated with patients and parents without the mediation of a coordinator.

In most empirical^{17–21} and theoretical^{11–16} articles the model of collaboration was not explicitly mentioned but most of the papers seem to indicate that MDTs take a multidisciplinary approach insofar the teamwork was described as the simultaneous and independent contribution of two or more team members. Only the mixed methods study of Sanders and colleagues⁹ included an interprofessional team approach where patients, parents and members of the MDT actively cooperate in the treatment process in order to co-create knowledge and improve the care of people with VSC and help parents cope with their child's condition.

As Liao and Roen¹⁹ pointed out medical professionals have more important role than psychologists whose work is seen as non-intervention because it is not medical and it is as such often side-lined.

The most often mentioned barriers to multidisciplinary collaboration were lack of financial, organisational and financial resources at hospitals and care centres for MDTs to be implemented and registered^{11–14,18}. The key barrier to collaboration, e. g. formation of MDTs in these centres is the lack of specialists^{9,12,13,18}. One fourth of the papers^{9,12,21} stressed the absence of confidentiality between team members, patients and parents as a barrier to collaboration process because sharing information can be distressing to parents to the point where they cannot participate in the shared decision making process.

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Two papers ^{14,20} pointed out the difficulties of diagnosis referred to as the time of diagnosis and the precise determination of VSC. The lack of cooperation between medical professionals and psychologists and prevalence of medicalised approach was highlighted as a barrier in one case ¹⁹. Only one study ²¹ pointed out the emotional distancing and difficulties of medical professionals to distinguish facts from assumptions as obstacle to collaboration process. One fourth ¹⁵⁻¹⁷ of the papers did not specify any barriers to collaboration process.

4. Ethical principles of MDT teams

The most commonly cited ethical principles were informed consent ^{11,12,14,16}, and shared decision-making ^{13,15,17,18,20,21}. However, only a minority ^{9,11,12,17} of papers provided an account of implementation of these two ethical principles. The papers ^{9,11,12,17} stated that parents needed to be educated about the condition of their child and that parental fears need to be considered in the decision making process. Yet there was lack of mention of how patients themselves growing up should be educated about their condition and actively involved in the decision-making process. Only two papers mentioned the involvement of patients in the decision making process ^{11,15}. Two papers ^{13,20} emphasized that the communication between MDT and parents/patients in the process of making an ethical decision should be open and should include the concerns of parents, but not children.

Discussion

The scoping review identified 12 studies that either empirically or theoretically provided an account of multidisciplinary teams caring for patients with VSC. Almost all articles stressed the importance of MDT, but under closer examination the exact nature of collaboration remained unclear. The prevalent approach seemed to be multidisciplinary, that is, collaboration in which different care providers work simultaneously but separately. The papers rarely elaborated on implementation of multidisciplinary let alone critically examine it. Research on MDT in other healthcare contexts suggests that it is not enough to have a unit of different health care professionals working together ^{23,24}, but the responsibility, knowledge and authority should be flexibly shared and team members should believe in cooperation ^{23,25-27}. However, the studies in our scoping review failed to address these suggestions as there are no indicators to assess the impact of the MDT which could lead to improved care for people with VSC.

The teamwork is usually coordinated by an endocrinologist, physician, and in a few instances by a psychologist, even though this was not always empirically assessed, because the exact nature of the relationships with the teams and their working practices were not revealed. The papers clearly demonstrate the dominance of medical professionals over other healthcare experts and psychosocial care in the core teams which necessarily include endocrinologists, urologists, and surgeon and to lesser extent psychologists, social worker, and ethicist.

Our scoping review confirmed the findings that tendency toward a more medical-oriented structure (predominance of doctors in the teams) of multidisciplinary teams leads to poor collaboration and efficacy ^{27,28}.

This was also partly confirmed by data on psychological support which is thought of and provided in terms of “alleviating emotional distress of parents facing the fact that they have a child with VSC”. Psychological support is provided to mediate relations between families and medical professionals, but it seen as addition to the treatment provided by medical professionals.

The account of psychological support revealed absence of child-centred approach and a lack of combined child centred approach with family-oriented care as there was no mention of what kind psychological support is provided for people with VSC, but only for their families. This was reverberated in ethical principles as only two papers mentioned that the decision making process and informed consent should include people with VSC. This might be since the majority of papers focused on infants and children, however these studies failed to address the role and implementation of shared decision making for them. The studies also did not refer to care of adults and transition of care from adolescence to adulthood.

The lack of inclusion of patients’ perspective and preferences in the treatment of people with VSC and shared decision making process in the examined literature is consistent with previous findings. According to these findings health care professionals stated that patient’s perspectives should be an important part of the meetings of the MDT, but do not consider it beneficial to the meetings of MDTs ²⁸. It is seen to be at the odds with professionals standards, and what is more medical professionals conflate shared decision making process with informed consent or there is no awareness of the former term ²⁹.

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Although some papers aimed to advocate for approach according to which teams educate their patients and even learn from them – the interprofessional approach which seems to de-hierarchize the knowledge relations between patients and medical professionals – they remain a minority within the current literature on medical collaboration in multidisciplinary teams working with people with VSC ⁹.

Limitations

The scoping review explored the existing literature on MDTs examining the collaboration processes and ethical frameworks. Some relevant studies might have been overlooked due to exclusion/inclusion criteria, e. g. conference abstracts and grey literature might have provided information from patients on the MDTs. Nevertheless, our review provides an overview of the existing literature on collaboration of MDT caring for people with VSC and provides important directions for further research that will hopefully lead to better care of people with VSC. Therefore we propose the following suggestions for future research: investigating the role of the health care professionals in the teams in the decision making process; examining the nature of relationship between patients and MDTs; examining the lack of care for adults and transition; more research on how MDTs can actually work together; researching new models of collaboration within the MDTs and how they relate to ethical dilemmas working with people with VSC: informed consent vs. competence and capacity of children and young people of children and their rights to participate in their treatment.

Conclusion

The scoping review revealed that teams caring for people with VSC are seemingly multidisciplinary. The collaboration among them lacks cooperation and synthesized discipline approach as one team member – usually a medical professional (an endocrinologist, a geneticist or a physician), rarely a psychologist or a social worker, coordinates the management process while the rest of the team members seem to work separately. Only a minority of team members come from disciplines such as social work or psychology. The most frequently cited ethical principles are shared decision making and informed consent, but both tend to focus on parents rather than on patients. Future studies should pursue empirical research on MDT by examining in the detail the process of shared decision making between MDT, parents, adults and children.

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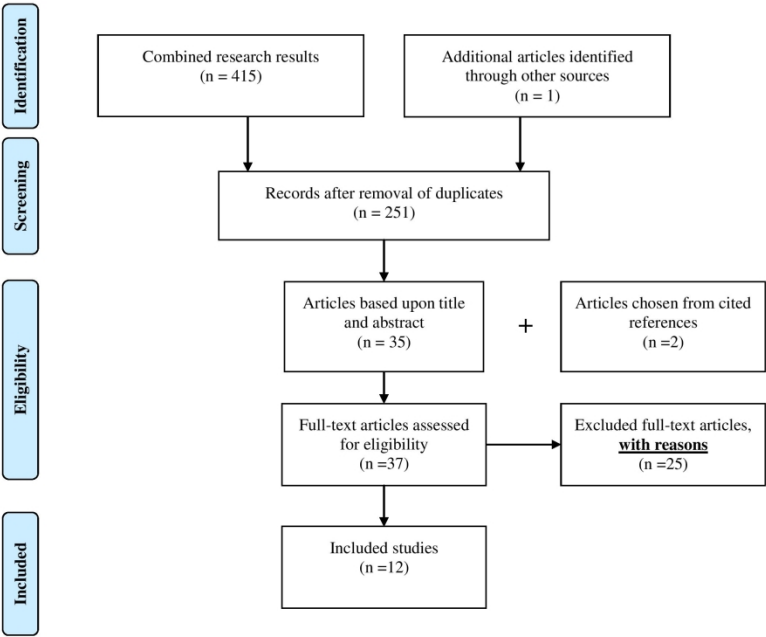
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Figure 1: Search process using PRISMA Systematic Review of Literature



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